A Background Paper on

Assistance with the Provision of Care

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Senior Citizens Secretariat
December 1985

SS083J 0001.0.0

FINANCIAL ASSISTANCE FOR CAREGIVERS

Introduction

In these days when single parent families, families with two working spouses and older couples living away from the nuclear family are becoming the predominant social patterns, we need to consider ways of assisting families in their care of elderly members. A recent study mentioned by Evelyn Shapiro from the University of Manitoba in her keynote address to the Alberta Association on Gerontology, May, 1985, indicates that, in spite of shifting social patterns, families still continue to carry the greatest burden of care for the older generation.

A study done in Manitoba shows that 36 percent of elderly needing care are attended to by their children, mainly daughters or daughters-in-law, with 60 percent of these caregivers "the meat in the sandwich generation" which takes care of her or her husband's parents and their own children while holding down a job.

Another 33 percent are cared for by their spouses who, although not working outside the home, face a different problem - one of being elderly themselves and experiencing fatigue, illness and tension intensified by this added care. Fengler and Goodrich[1] observed generally low morale in caregiving spouses with frequent problems being isolation, loneliness, economic hardship and role overload.

Another 19 percent depend on other relatives for care while 12 percent are assisted by neighbors or friends. Many of these careproviders are in the same work situation as those in the daughter (daughter-in-law) group but studies have not been made to determine the percentage working outside the home.

A recent time study, done in Manitoba, has calculated the hours needed for different care requirements:

Assistance with daily living -	9 hours per week
Assistance with limited mobility -	9½ hours per week
Assistance with daily living and grooming -	14 hours per week
Assistance with daily living, grooming, feeding, transferring -	27 hours

This is no trivial undertaking. The extra pressure being experienced by children, marriage partners, other relatives and friends often leads to situations which become unbearable and result in family breakdown or the inability of the caregiver to continue to cope. In both cases the institutionalization of the elderly person is very often the final result.

The Coordinated Home Care Program is an excellent way of providing many health and support services but, of necessity, it can provide care on an intermittent

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[1] Fengler, A.P. and Goodrich, N. "Waves of Elderly Disabled Men: The Hidden Patients", Gerontologist, Volume 19, 1979, Pages 175-183.

basis only. It can not provide continuing twenty-four hour care and supervision except on a temporary basis.

Faced with the problems encountered by careproviders, other countries and provinces have realized that more options need to be offered so those wishing to assist relatives need not be overcome by stress and fatigue. The Senior Citizens Bureau has encouraged some of these options in its reports, particularly respite care and adult day care. We cannot stress enough how critically important these and other such services are to both the elderly and their supporters. To the elderly they represent the chance to get out of the house regularly or occasionally to socialize and to engage in activities. To the supporters they are an opportunity to rest, socialize, do errands or take a vacation. These are valuable assists for the care-giving family. Financial help, which might relive the excessive burden placed on the family care system, is now being examined.

European Programs

Several European countries have programs of "Attendance Allowances" by which disabled persons, after a rigorous assessment of need, both financial and physical, are provided with funds which enable them, in part or in whole, to purchase the help of an attendant. This care may be purchased from family, friend or neighbor if home care is not available. Other plans provide monthly financial payments directly to the family member, friend or neighbor.

Norway's attendance allowance seems to be the best developed. Monthly financial support is given to the careprovider if the care involved limits the helper's possibilities of getting other employment or requires him/her to leave the work force. A person who has looked after an elderly or disabled relative is also entitled to a pension if the services have led to a permanent reduction in the possibilities of obtaining employment. A contract is made between the careprovider and the local home care office and help is considered and paid as home help and must be provided within the defined scope of home help service. Such care is supervised by home help and, if necessary, the caregiver is trained by a home helper.

Sweden's plan is similar to this. In 1982, 10,500 caregivers out of 70,000 home helpers in the country were relatives or neighbors being reimbursed at the same rate as other home help aides and being supervised by home help.

Program in the U.S.

In the United States, the State of Wisconsin, through the Community Options Program, can provide funding to individuals to purchase needed services. A care plan is developed with the person in need and the person is reimbursed up to the amount of public funding that would have been spent had that individual become a medicaid eligible nursing home resident. This program first started on a pilot basis in 1982. It is not specifically intended to assist family caregivers, but it is similar to part of the attendance allowance program.

Canadian Plans

A similar financial assistance program is already in place in Saskatchewan where Home Care districts may compensate a careprovider for assisting a member of the family if no one else is available. This is usually in remote areas. The relative becomes an employee of the Home Care Program and must take the training program given to all homemakers. The caregiver must also be available to serve others.

Veteran Affairs Canada has an Aging Veterans Program that is available to all war disability pensioners 65 and older who also receive War Veterans Allowance and to WVA recipients 75 and older. The program provides a maximum of $4,300 a year which the veteran may use for direct patient care, personal care, housekeeping and/or groundskeeping. This financial assistance is available only where needed benefits are not fully covered by other community programs. At present approximately 400 veterans in Alberta receive this allowance.

The veteran may either hire someone to provide service or the allowance may be paid to a friend or relative as long as he/she does not usually live in the patient's home and as long as providing care to the person has not been her/his usual function. In instances, where the dependent older person needs twenty-four hour care, the relative (friend) may live in the home but documentation from a doctor is necessary before this is allowed.

An additional Home Adaptation Service equips the veteran's residence with necessary alterations to a maximum of $2,500 and an Ambulatory Health Care Service supplies funds for specialized services available through clinics, out-patient departments, day care hospitals and day care centres. This may include physiotherapy, recreation, diabetic care, counselling and other related services. The maximum payment for this service is $500 per year. Another $600 may also be provided yearly to pay transportation costs to help eligible low income veterans who are unable to attend social activities. Only veterans in need of home care or receiving the Ambulatory Health Care Service may receive this last benefit.

These programs taken together, give excellent assistance to a family careprovider by making funds available for a relief caregiver, other care options and for transportation so the elderly person may leave the home for social programs. With any of these veterans' programs, the patient pays for care and sends in a bill each month to receive reimbursement. If the amount is dwindling too fast, the individual is notified that the yearly allotted funds are not going to last unless expenses are cut.

An assessment of the veteran's needs is made initially by a Veterans Affairs counsellor and a nurse. The nurse's part of the assessment is done in the client's home. In cases where a number of needs are identified, the assessment is carried out by a Health Care Team consisting of the Senior Treatment Medical Officer, other health professionals, counselling and administrative staff. All cases where assistance is provided are followed up by the Department of Veterans Affairs with the counsellor acting as coordinator.

When the program began in 1981, a nurse was hired on a contract basis for assessment and supervision. Now that the program is available to more

veterans, a full-time nurse has been hired both in Calgary and Edmonton. The rural area of Alberta is served from these two centres. Three phases of program expansion within the next three years will require a second nurse hired on a contract basis. Other staff involved in the program were already working for Veterans Affairs.

A plan based on tax credit or tax deductions was presented at the 1985 meeting of the Canadian Association on Gerontology.[2] One part of the program would allow a dependent elderly person to apply for tax deductions. To be eligible the person would first have to evaluated on the level of dependency. This evaluation would be based on current care level placement of daily living. A second evaluation of assets would be needed to determine the amount of tax deduction allowed. This evaluation based on economic variables would be done annually. Reassessment of health would also be done yearly. In this case the person pays for his/her own care which could be reimbursed by a limited tax deduction.

Another plan would provide tax credits to a family member who is paying for the care of a dependent elderly person. . The responsible caregiver would be able to claim to a certain limit the expenses of hiring someone to care for the elderly person while the caregiver is at work, and could also deduct the cost of hiring someone an additional 12 hours per month so the careprovider could have some recreational or rest time.

A third plan, like the European programs, would allow a full-time caregiver (relative or friend) to be paid an allowance. The specific amount would be minimal but would provide an income. In addition the caregiver would be entitled to continue participation in a provincially/federally organized pension plan if she/he participated in such a plan prior to retiring to care for the older person. The time taken off would be considered as a sabbatical with no penalty.

Issues Involved

All of these ideas presented here imply an attitudinal shift away from relieving families by institutionalizing elderly, to one of family provided services supported by the professional systems. It is, of course, understood that institutional care will still be necessary for those who are too ill to be cared for by families. Relief options such as respite beds, day hospitals, home care and adult day care centres will need to be developed further if any of these programs were initiated. The tax credit/tax deduction idea would probably be the easiest to administer but all of these programs would involve procedures that need to be carefully examined.

Assessment is an important element of each of these programs and could be based on current care level placement assessments. In Alberta such assessments could be made by Home Care staff who are already assessing applicants for their own program. When the single point of entry (as proposed in the model for coordinated assessment and placement) is in place, multi-

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[2] Canadian Association on Gerontology, Financial Incentive and Tax Considerations for Caregivers of the Elderly, Oct. 20, 1985.

disciplinary assessments can be done at the point of entry. The assessment would also need to determine what needs of the patient cannot be met by the family; how much time has to be expended on care; whether the caregiver needs training and whether the use of professional collaboration would allow the family to care more effectively for its elderly member. This would require the development of well defined criteria of family need.

Reassessment would have to review on an on-going basis both the patient and family situation to see how well the family is coping, and if help, financial or professional or both, is still required.

In some instances training may be necessary for the caregiver. A course has already been introduced in Montreal called Supporter Endurance Training[3] which needs to be evaluated. Who would be responsible for training is another issue to consider.

The situation in Alberta should be studied to see how many care providers in the province find themselves in stress situations because they are working outside the home as well as caring for a relative or friend, or because they themselves are unwell. We also need to discover how many would have been willing to assume caring for a relative or friend rather than institutionalizing them, but could not do so because of financial need or lack of relief care services.

What agency would be responsible for the administration and monitoring of such programs to ensure that neither the individual nor the programs are exploited and to coordinate these benefits with other services would need to be determined.

Because these questions need to be studied, the Senior Citizens Advisory Council plans to look more closely at the issues involved and gather additional information about assessment and training programs already in use, and about the success of these programs.

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[3] LEVINE, N.B., GENDRON, C.E., DASTOR, D.P. et al. "Supporter Endurance Training: A Manual for Trainers", Clinical Gerontologist, 2:15, 1984.